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ABSTRACT

James E. Gilliam is the author of a book entitled "Autism," published in 1981 by Charles C. Thomas Company. This brochure records an interview with Mr. Gilliam conducted by Burt Smith and later converted to narrative form for publication by Charlene Warren. Adapted from a series of radio broadcasts entitled "The Human Condition," the brochure is primarily concerned with the developmental characteristics and family relationships of the autistic child. Section 1 provides a description of the varying degrees and manifestations of autism, including a look at specific behaviors and degrees of intelligence exhibited by autistic children. Section 2 addresses the lack of professional agreement and firm data concerning the etiology of this disorder. Section 3 discusses the interrelationships occurring in the family of autistic children and stresses the importance of family support and acceptance to the autistic child's well-being. Section 4 presents long range considerations such as attending public schools, organizing support groups for families with autistic children, and the consistent treatment necessary for the autistic child. Section 5 recommends a firm approach with strong reinforcement for correct responses as an effective technique for the management of autistic children. The final section discusses services available to autistic children and their parents, with special reference made to the National Society for Autistic Children as an excellent source of information. (LH)

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James E. Gilliam, Ph.D., Associate Professor of Special Education at The University of Texas at Austin, taught emotionally disturbed children while he was an undergraduate student. He also taught normal children at the sixth-grade level prior to completing his master's degree. In his present position he is Area Coordinator for Emotional Disturbance/Autism as well as an educator.

He has authored monographs, teacher training materials, journal articles, and chapters for textbooks. His book titled *Autism* was published in 1981 by Charles C. Thomas Company.

"The Human Condition" radio series was produced by the Center for Telecommunication Services at The University of Texas at Austin and the Hogg Foundation for Mental Health. The series was broadcast weekly by stations subscribing to the Longhorn Radio Network from 1971 through 1982.

Adapted for publication by Charlene Warren
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On Autism

One might visualize an autistic child huddling in a shadowed corner, trying to hide, seeking isolation. This boy or girl just wants to be left alone—gives no response to a warm voice, and perhaps howls when someone extends a loving hand.

What is autism?

Autistic children suffer from a severe behavior disorder that is characterized by disturbances in development, in responses to sensory stimuli, in language, and in the ability to relate to people. Though it is rare (only 5 in 2,000 children are afflicted), autism is devastating in those families and extended families where it occurs.

Manifestations vary. Some parents report their children are extremely irritable, do not sleep well, reject food, do not develop as average children do. Other parents report babies extremely placid and content to lie in their cribs without being handled, crying only from hunger or the need to be changed.

Some of these very young children (autism usually develops within the first 30 months) are severely handicapped, with behavior almost uncontrollable. They engage in extreme amounts of body rocking, hand flapping, screaming, or muteness. Other children are more mildly affected and will speak. They can relate to other people and do academic tasks much like other children. The range of disturbance is great. Even those who are mildly affected will still have some problems that need special attention.

Behaviors of the autistic are similar to normal behaviors but to an extreme—average children sometimes have temper tantrums, and certainly shy children might withdraw from others. Making a clear distinction is essential. It is important to observe the child's typical behavior in response to different people, objects, environments, and situations. The autistic generally demonstrate their extreme behaviors in all of these areas.

Over two-thirds of autistic children are functionally retarded. Determination of actual intelligence is impeded by their behavior problems. They may be unable to accept instructions for testing; they may seem to be deaf when really they are not. On IQ testing, about 80 percent score very low. Assessing their intelligence with accuracy is difficult.

Cause

The etiology of autism is a mystery. Many theories exist but few firm data. The theories most acceptable to professionals now are those surrounding physiological and neurological disorders of the brain.

In early writings about autism, one prevalent concept was that parents, particularly mothers, were guilty of failure to nurture the child and due to that lack, the child developed in negative fashion. What real data have become available strike down that belief. Parents of autistic children often have other children who are normal and share the same characteristics as the average population. It needs to be pointed out that by the time mothers of these children are really taken into consideration, a woman may have spent years with a totally rejecting, unappealing child. Those trying years would be expected to take their toll in emotional stress and on the relationship.

Parents need support in the understanding that they did nothing to cause autism. This problem is a birth disorder or developmental disorder over which no one—at this point— has control.

Effects on others; reactions by others

It is not easy to keep nurturing an unresponsive, seemingly cold, and perhaps even hostile child. Family relations are severely strained. Parental guilt feelings can be a big factor because so many persons think of their children as extensions of themselves. Friends and relatives often reinforce feelings of inadequacy by suggesting the child is not being disciplined correctly or is just going through a stage. Perhaps most importantly, there are few professionals available to provide assistance, instruction or counseling on how to live with autism in the family.

Other children can learn to accept the autistic child. They recognize that this child is different; his behavior is such that they probably would not choose him for a playmate. On the other hand, with encouragement these average children can be a great help as peer tutors or playmates or even as teachers as they effectively model better ways to behave. Other children in a family seldom suffer as a result of having an autistic sibling. Rather, they seem to develop good management and relationship skills.

The reaction among siblings and parents has a significant effect on the autistic child. Where siblings are accepting, the autistic youngster may show marked improvement. For instance, one family with six or seven children has an autistic boy. The mother credits his progress to the fact that the other children never leave him out of anything. With a family this size, something is always going on in the household, and this boy is always included as part no matter how strange he seems.

Long-term aspects

The same principle of acceptance and active involvement applies to autistic children in school. Most of them can attend public schools as shown in demonstrations over the past few years. In addition to a well-designed curriculum and consistent discipline, the acceptance of the "different" child by teachers and classmates—their willingness to tolerate some inappropriate conduct—until the autistic child begins to learn to "follow the program" usually has an impact on that child and his/her behavior.

Within families, parents themselves have done a magnificent job of organizing groups where they can meet and discuss their problems. They bring in people who have information to offer them; they support one another. A good many things can be done for autistic children now. Probably most important is getting the child into treatment as quickly as one begins to suspect that something is wrong. As more and more people become aware of what autism is, earlier

diagnosis becomes possible. Next, treatment should be carried out both in school and in the home. This disorder requires 24-hour treatment for the benefit of the child.

Techniques for management

A major problem that autistic children have in working with other children and adults is their need to control their environment. They will tend to isolate themselves and block out a teacher's interactions or those of other children. Often if they do not get their way, they will go into a temper tantrum or refuse to participate in the group. One of the first things that the teacher has to do is to bring the child's behavior under control so that the child can effectively learn.

One example is a youngster who, instructed to do some simple imitation tasks, began having a tantrum, screaming and trying to control the therapist, to get the therapist to leave her alone. The therapist's approach was to continue intruding into the child's behavior, working as if nothing were unusual. The child attempted to retch, alarming the mother who began to run for towels. The therapist asked if the girl had ever actually vomited with such behavior. The reply was that she had not; the family had always retreated when she behaved in this fashion. So, the girl had been controlling the family and preventing their interfering with her. The therapist continued treatment, and the child did not vomit.

A teacher, similarly, usually has to intrude into the child's environment. The boy or girl is denied isolation and required to sit with a group, encouraged to participate. Situations are set up where the child, within reasonable expectation, must make some response. For instance, cookies are passed at snack time. Every effort is made to get the autistic child to speak or make some gesture before receiving a cookie. The requirement is put forth patiently, of course, allowing the child ample opportunity to react in some way. But if the child simply refuses to relate, there is no cookie reward. After several cookie-less snack times, this child may recognize that coming out of isloation is the only way to get what he or she wants.

That autistic children are very fragile and that demands on them could cause these boys and girls to fall apart and become psychotic was a prevailing belief for many years. It is now known this is not true. Autistic children seem to be very resilient, very much in control and trying to control others. So it is found that the best method with these children is a firm approach with strong reinforcement for their correct responses.

Parents need a great deal of support in management of behavior. Hardly any parents are *taught* how to discipline; they usually assume a style from role models, probably their own parents. They have not learned techniques used by professionals in behavior management, particularly behavior modification. They need instruction on directing the children.

Some parents, often by instinct, do manage well, and they should be congratulated and reinforced. They have usually given consideration to their interactions with their child and will probably know more about what works well with that child than the teacher will. A partnership is needed between teachers and parents so that they can work consistently, using in each place, school and home, those techniques that are known to work in the other place. This consistency of instruction provides a framework in which learning can take place.

Approaching the autistic child may be uncomfortable for those outside the close circle of family and school associates. Though making allowances for autism as one would for any handicapping condition, a positive approach that this child is pretty much like other children can be helpful. One would not want to provoke aggressive behavior by trying to rush the child into unwanted interaction, but warm and encouraging communication would certainly be appropriate.

Where can parents go for help?

Services to autistic children and their parents vary in different areas. However, all states have provisions for the early identification and assessment of handicapped children. Generally, any child suspected of

being handicapped at about the age of three is eligible for services. The parents or others who have knowledge about the child should contact the special education department of their local school district and inform the appropriate person (special education director, supervisor, psychologist, or other person in charge) that they are concerned that this child may have a handicapping condition.

They should describe in detail the reasons for their concerns and give any relevant information they have gained from physicians, nurses, or others who may have seen the child. At this point the school district is obligated to follow up and assess the child to determine if a handicapping condition is present.

If the parents are not satisfied with the appraisal, they have the right to appeal. All state education agencies are required by law to provide parents with a written statement of their rights regarding educational services to children who are handicapped or suspected of being handicapped.

In most states other agencies extending services to autistic children and their families include the state departments of mental health and/or mental retardation, departments of public health, intermediate school districts known by various names in different states (Education Service Centers, Board of Cooperative Educational Services, County Educational Service agencies, and others).

Finally, the National Society for Autistic Children or its state affiliate is an excellent scource of information about services available to autistic children—in all areas of the country. The address is:

National Society of Autistic Children
1234 Massachusetts Ave., N.W.
Washington, D.C. 20005
area 202/783-0125

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